

*by Rita Sanderson*

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### **Learn All You Can About the Illness**

Read at least one good, thorough book about your illness (be sure to check out the [Book Review](#)

section on this website), look for medical articles published by physicians who have specialized in the treatment of the Chronic Fatigue Syndrome/Chronic Fatigue and Immune Dysfunction Syndrome/Myalgic Encephalopathy (CFS/CFIDS/ME) and/or Fibromyalgia (FM), do Internet searches. A place to start is to thoroughly use this website, which contains significant much information as well as

[helpful links](#)

to other sources of information, subscribe to newsletters published by major CFS/CFIDS/ME and/or FM organizations, and subscribe to Internet sources that will automatically deliver information to you. Try going to a couple of support group meetings or using one of the many illness-specific Internet discussion forums. Education is one of the most important components in the treatment of CFS/CFIDS/ME and FM and knowledge will empower you.

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### **Interview a Physician as if You Were Hiring a Consultant (for Your Healthcare)**

When you first visit a physician, determine if the physician listened, was interested, and demonstrated enough knowledge about the illness. Trust your instincts. The initial visit is a data-gathering session and future appointments are to discuss issues in greater detail. Obtain and take medical records with you on new visits.

### **Clear and Concise Presentation of Medical History and Symptoms**

The goal is to make the most of your doctors' visits by having questions written down, not leaving things to memory and trying to schedule an appointment when you will be able to function at your best. As unfair as it may sound, patients are judged on their ability to communicate and on their behavior and appearance, especially during consultations with specialists. Always question new symptoms and don't attribute everything to CFS/CFIDS/ME or FM. It is possible to have several other co-existing conditions, and tests may need to be periodically ordered to rule out other problems. In order to maintain a good medical history, consider using a journal, notebook or a large calendar to record the status and changes of symptoms; what medications have been prescribed; dosages and if /when dosages were changed; effects of these medications; and record anything else that may have had an effect on your health-supplements, foods, exposures, and/or activities. Also, remember to explain your inability to, or difficulty in performing certain activities and functions so that these are documented in your medical records.

### **Patient Rights**

As a patient, you have a right to be respected, trusted, and be taken seriously by a physician. You have a right to timely feedback on test results and a clear explanation (in terms you can understand) of the diagnosis, treatment and prognosis. You also have a right to an exact copy of your medical records. (Guidelines for securing your records vary from state to state.) A patient should not be made to feel somehow guilty or responsible for having a complicated, recurring illness that his/her doctor doesn't know how to treat and manage. A patient needs to speak up when appropriate and if you have a difficult situation to discuss or resolve, consider bringing someone with you. There may be times you may have to go outside your HMO to get what you need.

### **Doctor Patient Relationships**

On the other hand, patients must be reasonable in their expectations and take responsibility for their care. If you have a doctor who is willing to work with you through the sometimes lengthy process of finding out which medications and therapies work best for you, then this could be considered a feasible arrangement. The goal is to develop a rapport with the doctor so that you can comfortably provide feedback about problems/treatments and have him/her respond in a respectful manner. Sometimes patients may not give a certain treatment enough time to work or to have it be adjusted to the right dosage, decide to make changes in the treatment on their

own, and may not even report the results to the doctor. As you continue to see a particular doctor, you are creating your medical history and if you depart from that individual, you can lose a lot of what has been shared or discovered and end up starting all over again. Of course, there are times when change is absolutely necessary.

### [Back to top](#) **Listen to Your Body and Become Attuned to Its Signals**

No doctor will ever know your body as well as you. Recognize there will be new boundaries that you cannot push through. Discuss and analyze what aspects of your lifestyle may be aggravating your condition and plan changes accordingly. Be extra careful on those days that you are feeling exceptionally bad; reconsider if you should go out (especially getting behind the wheel) to take care of a particular errand or visit on a really bad day. There are times that it may be better to postpone it, or call to see if someone else can take you.

### **Allow Yourself to Grieve for Your Loss of Wellness**

Grieving for your loss of wellness is a normal process consisting of several phases:

1. Denial and isolation (a defense mechanism)—a time during which we collect our thoughts.
2. Anger (a normal and even a necessary emotion) can be exhibited in a number of ways—sarcasm, gossip, compulsiveness, and intolerance. It is important to find appropriate ways to express and direct this anger.
3. Bargaining is when you try to cure yourself with good intentions and realize these efforts are in vain.
4. Depression can set in when you realize that neither anger nor good intentions will make the illness go away. It is normal to experience some degree of sadness when you confront your loss of health and previous lifestyle. You need to let this phase run its course, but if this sadness reaches a point that your basic daily functioning becomes extremely difficult, then professional intervention should be considered. In due time, you will regain a sense of proportion. You start to realize that, although this illness has closed some of life's paths, the journey can proceed on other, equally challenging and meaningful paths. It is helpful to take stock in what remains, rather than fixate on what is lost.
5. Accepting the illness and changes that this illness brings does not mean that you like what has happened, but that you are working with reality, striving to have more of life rather than less, and emerging as a "new" self.

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### **Chronic Illness Cannot Be Hidden From the Family**

Your family may not say much but it does see the effects of your chronic illness. When people are newly diagnosed, there is an enthusiasm and willingness by other family members to set aside their personal agendas for a while and help the patient rise above the problem. But when the problem appears to be ongoing, it can often drive people apart. The family members may not share the physical symptoms, but they may suffer fear, anger and grief from what has happened. Due to the disruption caused by the illness, there could also be feelings of resentment. Often problems prior to illness can escalate. "Words can sting, but silence breaks the heart" as Sefra Kobrin Pitzele reminds us in her book, *We Are Not Alone: Learning to Live with Chronic Illness*. Spouses/other family members may avoid asking how the patient is doing for fear of having to hear about it and deal with feelings. It is important to share and acknowledge each other's feelings, exercise common courtesy, and come up with a new definition of "normal" in order to keep the relationship alive. It is also important not to allow illness to always be at the center of attention and to build upon the common interests/experiences that hopefully still exist. Some families may benefit from counseling by professionals with an expertise in dealing with the impact/effects that chronic illness can have on the whole household.

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## Stay Emotionally Healthy

1. *Journaling* is "stream of conscious" writing about whatever flows from your mind. Keep notebooks handy to capture these thoughts. No one needs to read or judge it. It can be helpful to track the ups and downs of the illness, empty worries from the mind to paper, and/or record gratitude moments. An overactive brain can lead to feelings of anxiety, confusion, indecision, and mental paralysis. Every thought is a biochemical event that has an effect on body and mind functions.
2. *Use self-talk* and positive re-affirmations to tell yourself that you are doing the best you can and treat yourself with dignity, respect and love for who you are and not what you can do. Don't apologize for being ill or having limitations.
3. *Practice* some form of body/mind relaxation techniques, breathing exercises, and/or use meditation tapes.
4. *Change your outlook*—CFS/CFIDS/ME, FM or any other chronic illness will bring people to a fork in the road: one path can lead to bitterness, anger and despair; and the other can bring peace, acceptance, hope, and courage. When you cannot change your circumstances, then the only choice is to change your reaction and attitude. Moreover, changing how you get through daily activities should not take away from your intellect, sense of humor, and overall value. Do not measure your worth by how much can be accomplished. Sometimes your opinion of yourself may be based on inaccurate information or unreasonable expectations.
5. *Reduce stress*—organize your day so that you can be in control of your time and activities, allow a "cushion" of extra time to minimize rushing. Evaluate if a particular situation warrants the kind of reaction or attention that you're giving it. Walk away from stressful

situations that are not yours, and try to avoid toxic people.

6. *Seek a support system*—when you find that you are becoming more isolated and lonely due to the illness, seek and develop outside sources of support with people who can relate to your situation. Do pay attention to how you behave when receiving support (by not being too pushy, negative, or defensive). Participate in a support group for as long as you feel it is of benefit for you. Try to attend several different groups to find which one has the focus and style most compatible to your needs. However, appreciate the purpose of a support group—it is a "self-help" forum for encouragement, sharing and receiving information and ideas. It is unrealistic for individuals to receive answers to all their specific problems and even find the "cure". People need to realize that each person has his/her unique body chemistry and the results may vary significantly amongst group members. There is no "one path" to recovery. Remember that more often than not, the leaders are also sick, dealing with the same issues, and could use some assistance to keep things going.

7. *Spiritual needs*—when faced with an emptiness or loss of purpose, focusing on expanding and exploring your spiritual side (not necessarily through organized religion) can be very therapeutic. Prayer and meditation can bring solace, encouragement, and strength.

### [Back to top](#) **Improve Your Overall State of Health and Well-being**

Try to eat more wholesome, natural foods and consider adding nutritional supplements to boost and support your body systems (under the supervision of a health-care provider). Avoid "SCANT" (per Dr. Charles Lapp) which refers to sugar, caffeine, alcohol, Nutrasweet, and tobacco. Those individuals who have problems with bloating and diarrhea may want to avoid dairy and wheat products and in general, try to identify food sensitivities. Increase your intake of pure water to 8 full glasses per day and add some salt back into your diet (check with your doctor first if this would conflict with other medical conditions). Take extra good care of your teeth since they can be a hidden source of bacteria and toxicity. Engage in some sort of low level interval exercise (a few minutes of activity alternated by rest, then a few more minutes of activity until about 3 sets of brief activity are completed, also recommended by Dr. Lapp). Modify your home by making it more comfortable for you. Analyze what motions/activities cause unnecessary pain/effort and think about how to improve these. Reorganize your kitchen so that you reduce extra steps and stop putting things away that you use several times a day (like pots and pans). Accommodate the kitchen and/or bathroom with devices that help you deal with specific problems (like using a stool to sit on) and the bottom line is always "strive to simplify."

## **Resting and Pacing Are the Two Most Vital Parts of Adjusting One's Lifestyle**

Rest is necessary for energy conservation and a return to neutrality or "slow idle" before going to another task. When setting up a schedule, rest periods are just as important as work periods. Pacing is maintaining activities at even keel, usually at a much lower pace than healthy individuals, and breaking up the day into multiple work, rest and play segments. Switching between tasks will help to give certain muscles and body postures a break. Learn to prioritize

and decide what is most important for today, next week, what can be delegated to someone else, and/or which things may have to be left undone. If something important is coming up, then conserve your energy for that. Try to stay prepared for unexpected circumstances by having some extra supplies, batteries, medicines, bottled water, and food on hand in the event that you are unable to leave the house due to a flare-up of your condition, bad weather, or car problems. In short—be flexible and try to stay within your "energy envelope."

### **Incorporate Play and Laughter**

An important part of pacing in the work/rest routine is to have a little pleasure and not when all the work is done! Don't postpone fun until when you feel better or new medicine is found for a cure. You need it now! It is crucial to find ways to escape or distract yourself from the illness. There is more than one way to have fun and it doesn't have to be what you did before. Read uplifting/inspirational material, chat with friends, get some fresh air by taking a brief walk or sitting on a porch, or watch a funny tape or TV show. Look out for new things to try like container-gardening that can be done on a balcony or deck; attend a class or presentation (many local libraries offer free programs or lectures on various topics); treat yourself to a cup of tea at Barnes & Noble while you browse through magazines; listen to soothing music; and/or consider getting involved with a little volunteer or advocacy work. Look for small pleasures and things that still bring you joy and comfort. Every so often, it is important to put the "what if's" aside (with regards to what might happen if I go and participate in this activity) and take an occasional gamble at trying something different or going out somewhere. The outcome could turn out to be a very positive experience, the dreaded consequences may not be as bad as feared, and even if they are, it just may be worth it psychologically for the chance to break away from the drudgery of the daily grind.

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Non-invasive remedies may include trying various forms of adjunct therapies, such as hydrotherapy (vertically standing in fairly warm pool to mobilize lymphatic fluid via hydrostatic pressure and/or doing gentle movements in the water); bodywork—receiving therapeutic forms of massage, learning posture retraining exercises, such as the Feldenkrais method specifically designed to help individuals retrain their muscle movements and posture, and/or engaging in suitable stretching or conditioning exercises; simple treatments such as using cold/hot pack applications in an alternating manner (cool ice/gel packs covered by towel and applied to neck and shoulders until area is cooled off; switching to hot, moist towel or a hot pack which will improve blood flow.); and using shoe/orthotic inserts which may prevent you from walking on sides of feet thereby keeping the body in better alignment; and lastly, identifying and correcting perpetuating factors.

Of course, it is understandable that each of us will pick and choose those therapies that are

financially affordable or physically doable. However, the two key suggestions are not to give up hope and always try to take the best possible care of yourself physically, mentally, and spiritually. "*Working toward peace of mind rather than perfect wellness ensures having an attainable goal. Hope cannot heal us but it can help the healing process* ."—Dr. Katrina Berne.

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## References

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*The Fibromyalgia Advocate: Getting the Support You Need to Cope with Fibromyalgia, and Myofascial Pain Syndrome* by Dr. Devin J. Starlanyl, CA, New Harbinger Publications; 1st edition, 1999.

*Fibromyalgia, A Handbook for Self Care and Treatment* by Janet A. Hulme, M.A., P.T., MT, Phoenix Pub. 2nd edition, 1995.

*The Diagnosis of Chronic Fatigue Syndrome: An Assertive Approach*, by Drs. Paul Cheney and Charles Lapp, *The CFIDS Chronicle Physicians Forum*, 1991, pp. 13-19.

## More Resources

[Annotated booklists](#)

[CFIDS & Fibromyalgia Self-Help](#) . Resource for an extensive collection of articles, audio

material and on-line courses created by Bruce Campbell, Ph.D. specifically for individuals coping with CFS/CFIDS/ME and FM.

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